# Self-Management of Chronic Illness: A Patient-Family Education Campaign

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## Abbreviated Abstract

This project developed and produced three educational tools: a videotape, a patient organizer, and a Web-content module to educate cancer patients and their families on current techniques and trends in cancer self-management. The three products were tested through focus groups to ensure that the profiles, structure, and content of the media materials were effective communication tools. Quantitative testing was done of the finished materials to determine the extent to which the videotape, patient organizer, and Web-content module improved the understanding and behavioral outcomes of cancer patients and their caregivers with respect to self-management. This series will meet critical social and medical needs, as well as offer commercially viable products.

## Primary Investigator

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## Research Team & Affiliations

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## Total Budget

## Research Objectives

**AIMS**

1) To conduct focus groups to obtain feedback on the web-based materials.
2) To determine if the web module was effective in educating and motivating patients in the self-management of prostate cancer and to determine the impact of this education on patient wellness.

## Theory/Hypothesis

Many medical and emotional issues emerge when a person is diagnosed with cancer. Once the initial shock passes, many patients need to begin thinking about coping with or self-managing their illness over the long term. State of the Art, Inc's assessment of extant patient education materials revealed a major gap in informational materials available to support cancer patients and their caregivers around issues of self-management of the chronic aspects of this disease. It was hypothesized that interactive products, like the web-based materials in this study, would provide not only ease of access to research and information, but opportunities to engage with information in a way that makes it meaningful for the user as an individual. Social Learning Theory was used in the development of these materials.

## Experimental Design

### Qualitative Research:

Five focus groups were conducted. Three groups of survivors, family members, and friends (two racially-mixed and one exclusively African American); and two groups of health care professionals who serve prostate cancer survivors (one serving racially-mixed clientele and one serving a clientele with a large proportion of African Americans). Due to the disproportionate rates of prostate cancer among African Americans, special emphasis was placed on recruiting African American survivors, their family members and friends, and professionals who serve African Americans. The focus groups lasted two hours (approximately one hour and 15 minutes for demonstration and 45 minutes for the focus group discussion).

### Quantitative Research:

This study used a quasi-experimental, pretest/posttest design to determine if the web module was effective in educating and motivating patients in the self-management of prostate cancer and to determine the impact of this education on patient wellness. The study consisted of an intervention group and a control group. All participants were evaluated at baseline (Time 1), 30-day follow-up (Time 2), and 90-day follow-up (Time 3) with mail surveys to collect data about demographics, attitudes towards self-management of prostate cancer, personal characteristics, perceptions about their health, sense of control, self-confidence, self-efficacy, and reactions to the web module.

## Final Sample Size & Study Demographics

**Qualitative Research:** There were 25 participants in the survivor/family/friend groups; 68% (n=17) were African American. Most were related to a survivor (only 25%, n=6, were survivors). Survivors (in the group or known to others in the group) had been surviving prostate cancer from one to eight years. Participants or the survivors they knew ranged in age from 48 to 85 years, and the participants themselves were represented in all age groups ranging from the 30-39 year old age group through the 70-74 year old group. Four participants (20%) were in the low income group (under $20,000 annual household income).

**Quantitative Research:** The study involved 109 men who had been diagnosed with prostate cancer. Participants were recruited nationally from Washington, DC, Maryland, Virginia, North Carolina, California, Arizona, New Mexico, Alabama, Georgia, Louisiana, and South Carolina.

## Data Collection Methods

Focus groups and mailed questionnaires

## Outcome Measures

**Qualitative Research:**
program satisfaction; recommendations for improvement

**Quantitative Research:**
attitudes toward self-management; self-efficacy; adherence to medical regimens; and reported pain

## Evaluation Methods

**Qualitative Research:**
Focus group results were analyzed

**Quantitative Research:**
Change scores for those in the experimental group were compared to those in the control group.

## Research Results

**Qualitative Research:**
- Both the survivor/family/friends groups and professionals groups were positive about the proposed website. Both groups indicated that while some survivors, family members and friends would be willing to use the site, others would be resistant.
- The major concerns were about the target audience for the site (i.e., whether the site should be only for survivors or for the survivor and his family and friends).

**Quantitative Research:**
- Overall, after use of the web module, intervention participants were not significantly different than the control group on the primary outcome variables
- Race had an effect, with the "Other race" group reporting greater increases at 90 days than whites or African Americans at 90 days (i.e., they increased the extent to which they regularly tried to put what they learned on the web module into their daily routine). An interaction effect was found for income and time, with those reporting "more than $50,000" showing a steady increase over time. Education level was also related to self-management routines with those having some graduate school education showing lower scores than high school or college levels.

Intervention participants who reported positive perceptions for various attributes of the web module, reported feeling confident in their ability to change their behavior and incorporate self-management into their lives. The intervention group also reported that they would recommend the web module to a friend, felt that the information on the web module was easy to understand, and that the website was good or better than others they have seen.

## Barriers & Solutions

There were challenges in recruiting participants for this study. The materials were designed to address the needs of men across a broad spectrum of experience with prostate cancer. Our recruitment criteria thus focused on men newly diagnosed with prostate cancer, and men who had been treated with surgery. Initially, "newly diagnosed" were defined as no more than three months from a diagnosis. Low numbers forced us to expand our definition of "newly diagnosed" first to six months and later to one year from diagnosis. Though this resulted in more recruits, overall recruitment was still very slow, which suggested a reluctance in this cohort for participation. Ultimately, recruitment took more than twice as long as anticipated.

## Product(s) Developed from This Research

Prostate Cancer for Men and Their Families; Colorectal Cancer for Men, Women and Their Families – a web-based program designed to educate and motivate patients and their families in the self-management of prostate cancer.